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AUTHOR Ashline, Melissa
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ABSTRACT

This review of the professional and programmatic literature in the field of developmental disabilities focuses on ways in which individuals with developmental disabilities and their families are becoming increasingly involved in program evaluation and quality assurance efforts. Three major movements are having an impact on this activity: state and national consumer empowerment efforts which include formal instruments and protocols to assess consumer satisfaction with services; Total Quality Management (TQM) which relies on the customer to drive the system; and the movement toward increased and improved consumer-provider partnerships (for example, home-school partnerships). The review indicates that: (1) consumers are empowered by having effective control of the money spent on their support, but a power gap exists between parents/consumers and officials since schools and service agencies possess and control the services needed; (2) applying TQM to public services is problematic, as TQM addresses problems singularly with single loop systems, while public sector services must concern themselves with many multifaceted problems; and (3) the experience and knowledge of parents should be used as primary sources of information in decision making, but professionals need training in parent support and involvement. (Contains approximately 40 references.) (JDD)

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CONSUMER INVOLVEMENT IN EVALUATION AND QUALITY ASSURANCE EFFORTS:

REVIEW OF CURRENT EFFORTS IN THE FIELD OF DEVELOPMENTAL DISABILITIES

by
Melissa Ashline, M.P.A.
supervised by
Anna F. Lobosco, Ed.D.

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Over the last decade, the developmental disabilities service system has shifted its direction dramatically; it is often characterized as "a shifting paradigm." Until recently, the service system for individuals with developmental disabilities was far more rigid and structured. Professionals, viewed as more knowledgeable than parents or other lay people, would identify what they felt was the appropriate program or package of services for an individual based on a categorical diagnosis. The major focus of services was institutional, or mini-institutional when they were available in the community. The individual with the developmental disability was considered a patient or a client and all emphasis was placed on the disability, the program and the goals. Programming was based on a deficit, or medical, model.

Presently, the goal of the service system for people with developmental disabilities is for service providers not to focus primarily on identifying weaknesses, deficits, and disabilities, but to identify the strengths, the abilities and the contributions that individuals with disabilities have or can make. The purpose of this identification is to allow providers to help the individual function in the community. The service delivery system is changing to provide flexibility and choice for individuals and families. There is a renewed focus on natural supports and services, new roles for providers as brokers and consultant; new roles for employers and community organizations; use of "generic" community services like transportation, day care, housing and health; and customer satisfaction.

Such a shift has an inevitable effect on program directions, program outcomes, and accountability efforts. Recent efforts have been designed to assure the involvement of primary consumers (individuals with developmental disabilities) and secondary consumers (their family members) in all aspects of programs and policies which affect their lives. These individuals are

giving life to the term "consumer-driven" by becoming involved in decision making on the personal, programmatic and fiscal levels.

This increased involvement means that they are also involved in defining quality and in efforts to assure quality in the services and supports which affect their lives. The shifting paradigm means that standardized testing or experimental designs for testing the effectiveness of a particular treatment are less likely to occur than an evaluation design which relies strongly on functional measures, customer satisfaction and stakeholder-based evaluation.

A review of the professional and programmatic literature follows; this review focuses on ways in which individuals with developmental disabilities and their families are becoming increasingly involved in program evaluation and quality assurance efforts. Three major movements are having an impact on this activity: state and national consumer empowerment efforts which include formal instruments and protocols to assess consumer satisfaction with services; Total Quality Management which relies on the customer to drive the system; and the movement toward increased and improved Consumer-Provider partnerships (for example, Home-School partnerships.) Each of these movements is being viewed with particular emphasis on how it is changing evaluation practice for programs serving individuals with developmental disabilities and their families.

In New York State, for example, the commitment to each of these movements is radically changing the service delivery system. Intended outcomes, accountability efforts, quality indicators and quality assurance measures are being redefined and radically changed to complement the service delivery system as it evolved under the shifting paradigm. This is in response to recent changes in major federal programs which are redefining the service delivery

system for individuals with developmental disabilities. Federal mandates such as the Developmental Disabilities Assistance and Bill of Rights Act have been moving in this direction for almost a decade. As other pieces of federal legislation (i.e., Individuals with Disabilities Education Act, Rehabilitation Act, Americans with Disabilities Act, and the Technology Related Assistance for Individuals with Disabilities Act) are reauthorized these principles and concepts are being included. In the field of developmental disabilities, the impact of this shifting paradigm on evaluation theory and practice will undoubtedly be significant.

CONSUMER EMPOWERMENT

The shift from specialized institutional care to support systems requires a shift in approaches for judging results. In redesigning the service system to promote quality assurance, providers and consumers collaboratively establish updated values and clear, consistent expectations. Areas of concern include "personal development, community participation, self-determination, economic independence, consumer and family satisfaction, and improved efficiency" (Gardner, 5.)

Empowered consumers achieve these valued outcomes through effective control of the money spent on their support. An indirect control of money flow for the consumer is a direct involvement in evaluating and assuring quality. For consumers with disabilities the current provider-driven system must still be further matched with negotiated consumer ideas. This requires confronting questions of whose expectations must be satisfied and the amount of choice given consumers (Sundram, 22.)

Implementing quality requires a change in processes, evaluation and focus. Service providers, then, must also become actively involved in assessing how well the values, plans, and policies are actually implemented. If all processes embrace quality outcomes, the environment will begin to meet individual needs. These outcome-based performance measures use such priority outcomes as dignity, respect, security, and rights, which transcend particular programs and services (Gardner, 4.)

Federal oversight with strong, streamlined federal policy would hold direct care homes accountable for compliance with service laws. A computerized national information system could facilitate inculcation of the comprehensive quality improvement. The decentralization of specific standards necessitates improvements in state regulations and accountability measures designed to protect vulnerable populations (Gettings, 8.)

The "recognition that quality is different in different settings and for different people" requires that the system accommodate individual needs. Decentralizing the system accommodates a focus of quality life for persons with developmental disabilities where quality is found in the achievement of desired outcomes. Quality assurance and monitoring might contribute to the improvement of services and by recognizing that persons with developmental disabilities are vulnerable to abuse and neglect in the community (Lakin, Prouty, and Smith, 2-3.)

Person-centered planning allows individuals to choose their own definition of quality of life by asserting preferences and desires. Preferences may change, so service providers or funding/oversight agencies must review and redesign living arrangements and daily activities as needed. Although the individual makes all final decisions, true control will come when people don't have to wait for formal system evaluation. Particularly those with severe disabilities, who

don't have much control over their boundaries, should be given control to "fire" service providers, and to redirect funds to "purchase" alternative services (Smull, 6.)

Support systems work best in a circle, in which quality assurance monitoring boards visit the site twice per year. These visits act as the bridge of the circle, as they assure that the living arrangements and the support plan provide a healthy and safe environment in the opinion of the individual, the representative, and the review team. If the services documented in the support plan are not being delivered, nor having the desired effects and are not satisfactory to the individual, the service provider must respond to the results of the evaluation, stating what actions will follow, and by whom they will be taken (Smull, 7.)

Creating a partnership between caretakers and consumers enhances the knowledge of both parties in setting and achieving goals. The partnership forms a loop of support made up of consumers, advocates, family members, providers, government staff members, and concerned citizens; continuous quality improvement depends on this multiple perspective approach. The team is responsible for gathering survey information and selecting areas for improvement (Wilson, Clarke, and Brodsky, 11.)

Positive and critical feedback are necessary to reach group or program potential. The steps involved: an assessment of needs; the development of a program logic model; the development of an evaluation plan; the development of a report format; and the distribution of results. Upon dissemination of results, the group enters discussion and begins planning improvements (Godley, 6-9.)

However, a power gap exists between parents/consumers and officials since schools and service agencies possess and control the services needed. Although consumers have legal rights,

they often lack the information on laws, regulations, special education language and how the system works, required to successfully demand services (Ferguson, 41.) Instead, consumers depend on schools to inform them of what programs and services are available.

As a result, parents feel underserved and believe that their children are neglected by the system. Parents often view teachers as well-intentioned, but inept or restricted by the administration or by their own lack of knowledge. Sometimes teachers reject these families because of mistaken beliefs that children with disabilities would harm other children (Ferguson, 42-43.) Consequently, the parents of children with disabilities need to be a mixture of decisionmaker, advocate, special education teacher, case manager, and program evaluator.

Educational Decisionmaker: The Individualized Education Plan (IEP) legislates parent involvement in choosing their child's course of study. Parents usually assume a passive role either by choice or because of a lack of support (Allen and Hudd, 133-4.)

Advocate: Advocates encourage "a wide scope of activities intended to secure more or better services for children." Advocacy "requires technical knowledge of available services, familiarity with statutes and laws, and the ability to exercise sophisticated strategies of influence" (Allen and Hudd, 134-5.)

Teacher: Parent teaching creates a cost-effective opportunity to link the school and home, and to train parents to be better caretakers. Parents provide continuity between intervention and home experiences (Allen and Hudd, 135.)

Case Manager: Parents coordinate services because they know what services the child needs and no one else assumes the coordinator role; also, service coordination networks

often add more limiting bureaucracy. Effective case management is difficult for parents due to time burdens, difficulty in entering the service system, and a lesser knowledge of the resources available and the procedures for securing these.

Program Evaluator: Parents use the programs, and so may best assess them. It enhances the parents' sense of control and the consistency between program and home environment. However, parental monitoring may replace formal evaluations, since few parents have the skills to design and implement an evaluation. Also, some may feel uncomfortable criticizing a program in which their child is currently enrolled (Allen and Hudd, 136.)

"Individualizing parent involvement to suit the needs and preferences of each parent" requires greater attention to parent training, needs assessments, and institutional flexibility. Professional support and a balance between parents' rights and professionals' responsibilities must exist (Allen and Hudd, 138.)

TOTAL QUALITY MANAGEMENT

Total Quality Management is a participative, decentralized system of management geared for continual positive change based on statistical evaluation of data. Improvement is based on both (individual) outcomes and systems process. It also requires an understanding of the meaning of quality and the importance of multiple customers; "customer" meaning anyone who uses outputs.

The intent of TQM's continuous evaluation is not to find better standards, but to find better processes for gaining optimal outcomes. Often, several demonstration projects, experimenting with theoretical changes derived from evaluation data, are implemented at the same time. The results of these efforts are then measured and process systems failures are continually weeded out.

Quality processes provide intrinsic incentives where profit acts as a disincentive. It must be understood, though, that quality has multiple dimensions: performance, reliability, conformance to specifications, durability, serviceability, aesthetics, marketability of features, and perceived quality. Often, applying TQM principles in complex public sector organizations is considerably problematic (Tobin, 11.)

Public sector organizations have a unique set of goals and experiences that TQM ignores. David Osborne, in his article "Why TQM is Only Half a Loaf," explores five additional principles which made TQM a success in several public organizations. These are creating competition, becoming an agent of solution, empowering constituents, saving money and defining the central purpose to facilitate a constancy of purpose (Osborne.)

As monopolies, government organizations are forced to be competitive in seeking suppliers, since it is often the only source of competition and improvement. This competition is in direct contrast to Deming's fourth point: to end rewarding suppliers on the basis of money alone. Contracting out to the lowest bidder has dangerous implications both for supplies and outcomes. Fiscally, the government would be strengthened by earning and saving public monies in other ways. Gainsharing allows agencies to retain savings in the agency budget, thereby encouraging responsible spending and saving (Walters, 41.)

The threat of privatization is the only other current source of competition for government organizations. TQM is often implemented by labor and management to stave off efforts to privatize services. Although it benefits both parties to implement TQM in this instance, it is not an easy task, nor does mutual support guarantee success (Walters, 42.)

Successful public sector agencies change from providing service delivery, to being an agent of solution throughout society. This means creating opportunities for communities and non-profits to provide preventive and other services. Currently, government control is being pushed into communities. For the public sector, this empowerment of people creates self-sufficiency of the constituency, ultimately strengthening the government (Osborne.)

TQM also ignores the public sectors' multifaceted mission, focusing on the business profit motive. Each agency often has several conflicting purposes, as well as layers of bureaucracy to muddle the process. The constancy of purpose then is irrelevant without a definition of the central purpose(s) and clearing away the regulations and line-item budgeting which slows the process (Milakovich, 195.)

TQM, like most quality assurance initiatives, addresses problems singularly with single loop systems. Public sector services must concern themselves with many multifaceted problems. The regulations and standards themselves must be analyzed each time the quality assurance activity is applied. Otherwise, regulations based on outdated values will be reaffirmed by efforts which mean to override those beliefs (Sundram, 2.)

James E. Swiss in his article "Adapting TQM to Government" considers the inadequacy of TQM's singularity in assessing quality of service provider agencies. TQM requires the reduction of variability, as it will result in better quality and dependability. Swiss points out that

uniformity of process is too complicated in any service oriented organization (357.)

First, service industries are labor intensive, which means production and consumption occur simultaneously. Second, the consumer evaluates not only the result of the service, but the behavior and appearance of the provider. [Quality indicators include access, communication, competence, courtesy, creativity, reliability, responsiveness, security, tangibility and understanding.] Finally, no clear consensus exists as to which processes should be tracked and standardized for the street level bureaucrat (Swiss, 358.)

Swiss also discusses the difficulty in weighting or singling out the most important customer. The diverse interest groups often have vague and conflicting goals. Sometimes, the interest groups or direct recipients of services and the ultimate customers (society) are in conflict over needs. The "buyers," or taxpayers are not always recipients of the services, but should still have a voice (358.)

Surveys are useful in gathering feedback from the public. Unfortunately, public opinion often reflects only highly publicized events and lacks objectivity. Incorrect or uninformed survey results will entrench problems such as blaming individuals for systems failures (359.) The results of this and the focus on process are short term vision and goal displacement.

TQM advocates focus on processes, while public agencies historically adhere to regulations. Outputs have always been "politically controversial and difficult to measure." In addition, budgetary concerns, the practice of gaining prestige by exerting control over inputs and legal requirements to abide by strict procedural rules causes government employees to focus inward (Swiss, 360.)

The culture of government is structured to be open to external forces due to our

democratic society. The culture is further weakened by the high turnover rate of top level managers and politicians (Swiss, 360.) Furthermore, the top level managers possess little control in implementing change, while the politicians have little incentive to focus on long-term goals such as quality, productivity, and efficiency (Milakovich, 195.)

Too often, labor groups are ignored in the process of implementing TQM. In many states, the Quality Initiatives implemented do not have labor representation in the upper-level committee. In fact, the deployment plans often call for a "top-down" management approach. The only "team-building" is between public and private sector administrators (Nyilis, 99.)

New York State has met with success in implementing Quality through Participation, a form of TQM. New York's QtP fosters a partnership between labor and management, based on previous cooperative work in confronting such issues as "health, safety, quality of work life, employee assistance and child care" (Nyilis, 63.) Through negotiations, the state contracted agreements with the unions to explore quality concepts and opportunities for joint change, as well as to establish employee flexibility for deployment.

TQM and the government must continue to make amends in the human resources department where issues of compensation, labor relations and training and development are turned upside down by TQM. The government must end practices such as seniority based promotions, performance appraisals, the merit system, pay-for-performance and quotas, as these contradict TQM goals and objectives to create cooperative efforts (Hyde, 33.)

The current problems of performance appraisal include the focus on rule by negative reinforcement and competition. The focus destroys morale, motivation and creativity: the most important factors to creating quality. More so, the focus diverts attention from the real problems,

that is the systems' faults. TQM attempts to solve this by implementing team based appraisal systems whose focus is on finding and promoting solutions to systems failures (Milakovich, 203.)

The current systems philosophy is so far removed from TQM philosophy that the change is often implemented in small steps. For compensation, this has meant using pay banding and group incentive mechanisms. However, these are already under attack for creating more problems than they solve (Hyde, 34.) Further steps might include gainsharing and knowledge-based compensation for base pay deferential (Walters, 41.) Recruiting applicants, selecting employees and human resource planning for future needs are among the important steps to consider in hiring for quality.

According to the American Society for Training and Development, the primary statistical concept of concern is variation. Two types of variation exist: normal and abnormal variation. Normal variation is a result of the everyday interactions within the organization. It is chronic or cyclical, and therefore predictable, but never completely absolved (Diagnostic Tools.)

Abnormal variation results from extraordinary events and shifts in society, politics and economics not inherent to the organization. Although "sporadic and unpredictable," abnormal variation may be completely eradicated through organization processes. Differentiating between the two types of variation saves an organization from absorbing abnormal variations into the system (Diagnostic Tools.)

The basic statistical tools include flow charts, tally sheets, Pareto charts, Histograms, cause and effect diagrams (decision trees and fishbone diagrams), scatterplots, information systems charts, run charts and control charts, as well as other diagnostic tools. Mainly visual

tools, the various diagrams facilitate quick analysis of complex data. Some may easily be done by hand, such as the tally sheet and the cause and effect diagrams (Diagnostic Tools.)

CONSUMER-PROVIDER PARTNERSHIPS

Integration policy includes both full inclusion and the Regular Education Initiative (REI.) REI involves the sharing of responsibility among all educators for children with developmental disabilities (Rossman and Anthony, 2.) Full inclusion fosters diversity in education which helps educators attain the goal of creating strong, personal identities to counteract the "melting pot's" homogenizing expectations (Pfordresher, 7.)

The positive effects of integration and diversity in the classroom benefit students with or without disabilities. First, it creates a national culture which admits all voices, thereby legitimizing people with disabilities by encouraging vocalization and affirming identity through interaction with similar peoples. In addition, diversity allows discovery of self through comparison to and discovery of other realities (Pfordresher, 8-9.)

Problems exist, however, since including diverse elements in the new curriculum partially sacrifices the current curriculum. A potential threat to true diversity arises from politically correct diversity. Also, it is difficult to define "different" and purposefully find the basis of difference, or the essence of diversity. Finally, it is also difficult to define "excellence" and to rediscover what is an excellent accomplishment (Pfordresher, 10-11.)

The controversy surrounding integration is instigated by several opponents, including behavior disorder advocates, and learning disabled advocates. Most opponents feel that regular

education's perspective has never been discussed in the debate. This group finds integration policy confusing and feels the proposal is not practically feasible, but rather inconsistent with regular education reforms (Rossman and Anthony, 5.)

Behavior disorder advocates believe that integration will jeopardize what minimal services exist for this group. Behavior problems in the regular classroom are dealt with as the responsibility of the student, and are dealt with through punitive disciplinary action (Rossman and Anthony, 6.)

Learning disabled advocates state that large differences in skills exist between a mildly disabled student's ability and the regular classroom curriculum, which stresses the mastery of specific content. In addition, this group asserts that regular classrooms lack the instructional strategies necessary for the learning disabled whom require intensive, small-group instruction. These demands are believed to be too great for the regular classroom. Finally, many believe that integration is cost savings driven, and that funds for special education will diminish as it merges with regular education budgets (Rossman and Anthony, 6-7.)

Teacher controlled, whole group instruction systems present knowledge as facts. The curriculum, often sanitized (rendering some controversial groups voiceless) and skeletonized for lower tracked students, lacks an emphasis on problem-solving, and higher order thinking skills. Restructuring classes to be student centered, with small heterogeneous groups for which the emphasis would be engagement in learning, cooperative problem solving, and a constructivist approach, would better serve all students (Rossman and Anthony, 15.)

Changes in family structures affect the providers' role, relationship with and therefore the ability to work with the child and family with a disability. Sociohistoric changes account for

"the disproportionate decrease in the standard of living of many children and families in the United States. Poverty stricken and "working poor" share or comprise the social phenomena of high infant mortality rate, poor health, lack of childcare, homelessness, increase in crime, and poor educational outcomes" (Hanson and Lynch, 286-294.)

Deficiencies in one of the three dimensions of development -formal schooling, family and community supports - may create challenges for the child with disabilities throughout life. (Pallas, 16.) Growth and learning can only be understood in relation to the various environments in which the child lives, learns from, is affected by, and interacts with others. Professionals do best to assist parents in meeting goals since parents know the child, while professionals know which methods and strategies will develop needed skills (McConachie, 7-10.)

The experience and knowledge of parents should be used as primary sources of information in decision-making. Instead, informal decisions are often made by administrators, while parents are involved only in the gathering or presenting of information. Also, what resource teachers feel parents should be involved with and what they actually do involve parents in is much different (Schuck, 26.) Some parents are not prepared to participate and some educators lack sensitivity in dealing with families.

Advocacy groups are excellent strategies for parents to secure integrated options. Groups become better informed, making it easier to influence policies on integration. Specific strategies might include the media, influential school administrators and others in the school system. Some work with other advocacy organizations and find legal consultation helpful (Hamre-Nietupski, 253.)

Despite attempts by parent groups to encourage partnerships, professional preparation is

still lacking. Professionals need training in parent support and involvement. A training program should involve presentations, role playing and simulation games created by parents. Educators may also become involved with families of children with disabilities, to gain experience and insight into the life of a child with disabilities (Schuck, 27.)

Changes need to be made in rules and procedures, special programs, distribution of authority and decision-making. For example, students and teachers could be placed in self-contained units responsible for learning across the entire range of curricula. Also, the budget should provide more than minimal resources for unexpected and special needs (Mittler, 14.)

Implementing better information systems would enable leaders to redeploy resources as needs arise. This might include concentrating information, resources, and decision-making to those closely accountable for the education of students in their charge (teachers and administrators.) Localized information bases allow agencies to develop policies relevant to the needs of area consumers. Administrative control is decentralized to Regional Directors, who have the responsibility of meeting regional needs of the population (Mittler, 14.)

Ideally, consumers and family members should be involved with policy formulation, program planning, implementation of decisions and evaluation. Parents tend to be more involved in the complete process in smaller educational or preschool integration programs. Partly, Individualized Educational Planning has created this involvement; secondly, parents are beginning to be accurately viewed as the primary educators in the development of children.

Integrated settings, particularly private preschool or daycare environments, have implemented the quality processes discussed throughout this paper out of necessity. Staff, in addition to meeting basic requirements, are screened for compatibility with the integration

philosophy and emotional investment in the population to be served. The system develops staff capabilities through library resources, inservice training, informal consultation with health staff, and team information exchange and problem solving. Interorganizational support systems also assist staff in maintaining updated services for consumers.

Parents, as the more intensive service providers for their children, are often given the same training opportunities as staff. Meetings and conferences allow staff and parents to discuss problems and solutions. Parent Advisory/Support Groups evaluate, oversee and plan future trends of the daily operations of the classroom. Finally, some parents choose the physical and educational placement of their children.

However, inclusion outcomes often vary due to local context: for example, the size of urban districts constrains outcomes. Educational leadership either hinders or facilitates integration initiatives. The regulatory overload, and contradictions in state and federal regulations also affect outcomes, as well as the state fiscal situation. Success of these programs requires political, technical and cultural support (Anthony, 7-8.)

Systemic change, the formal incorporation of integration into policy statements, requires leader's commitment and/or the political viability of integration. The planning process populace (committees which represent buildings or districts) do not sufficiently represent consumers. They also possess little formal authority to determine the allocation of grant monies or shape the implementation of integration (Anthony, 10.)

Systemic change assumes that any change in education reverberates throughout the system and that all levels (local, state and federal) must be congruent for program success. Critical questions to ask in creating systems change: Who will make the decisions affecting students?

How will services be coordinated? What learning environments are required for a diverse and challenging student population? (Rossman and Anthony, 8-10.)

Accountability for student outcomes is the responsibility of site-based management. Shared decision models, used by site-based management councils, allow parents to participate (Rossman and Anthony, 13.) However, regulatory overload and conflict still restrict the flexibility and coordination of appropriate funds (Rossman and Anthony, 14.)

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